CONCLUSION

# Excellent Palliative Care as the Standard, Physician-Assisted Dying as a Last Resort

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To understand the role of physician-assisted death as a last-resort option restricted to dying patients for whom palliative care or hospice has become ineffective or unacceptable, one must understand how frequently and under what circumstances that occurs. If all such cases are the result of inadequately delivered palliative care, then the best answer would be to improve the standard of care and make the problem disappear. Most experts in pain management believe that 95 to 98 percent of pain among those who are terminally ill can be adequately relieved using modern pain management,[1] which is a remarkable track record—unless you are unfortunate enough to be in the 2 to 5 percent for whom it is unsuccessful. However, among hospice patients who were asked about their pain level one week before their death, 5 to 35 percent rated their pain as "severe" or "unbearable."[2] An additional 25 percent reported their shortness of breath to be "unbearable" one week before death.[3] This says nothing of the physical symptoms that are harder to relieve, such as nausea, vomiting, confusion, and open wounds, including pressure sores, which many patients experience.[4]

Of course, dying patients do not have the luxury of cleanly separating their physical suffering from their psychological, spiritual, and existential suffering.[5] These common physical symptoms are only part of the puzzle of suffering at the end of life. We now know from Oregon that many patients who contemplate ending their own lives under the Death with Dignity Act have these physical symptoms but also report that tiredness with the process of dying, feeling out of control, and lack of meaning are frequently the most important reasons for requesting a hastened death.[6] We also know that dying patients who con-

sider hastening their deaths have trouble envisioning a meaningful future and that they score high on hopelessness scales.[7] Some patients who consider ending their lives under these circumstances are clinically depressed, but others are not, and none of these patients evaluated by a psychiatrist under the Death with Dignity Act was found to have distorted judgment from depression.[8] The reality faced by dying patients and their families in terms of suffering, even in the best of hospice programs, is much more complex than is ordinarily acknowledged. Eighty-five percent of the 171 patients who died with the assistance of a physician under the Oregon law were simultaneously enrolled in a hospice program,[9] so for them the dichotomous choice "palliative care or physician-assisted death" was clearly insufficient.

What are the effects of current prohibitions against access to physician-assisted death? Practices of last resort, such as physician-assisted suicide, that are illegal outside of Oregon are difficult to study because clinicians and family members could be criminally liable if they openly admitted to having participated. In reality, U.S. policy outside of Oregon would more aptly be characterized as "don't ask, don't tell," as the medical and legal professions have shown little enthusiasm about actively pursuing such cases through either legal or professional channels. Empirical studies on the illegal practice of physician-assisted death suggest that it accounts for a small percentage of overall deaths everywhere it has been studied, although in select populations, such as AIDS patients in San Francisco before the introduction of protease inhibitors, the practice may have accounted for almost 50 percent of deaths.[10]

If the "don't ask, don't tell" policy is working reasonably well, why not just leave it alone? The answer to this question is that it is not working well, for several reasons. First, access to the option of physician-assisted death is uneven and unpredictable, probably depending more on the physician's values and willingness to take a risk on the patient's behalf than on the patient's values and clinical circumstances.[11] Second, explicit conversation carries some risk, so patients, families, and their medical providers may communicate tacitly, with a wink and a nod instead of forthright conversation, with the concomitant potential for dangerous, possibly lethal misunderstandings in this delicate area.[12] Third, there would be no guarantee of adequate palliative care being in place before last-resort options were considered, so it would be more likely that a hastened death would be implemented in the absence of standard of care for the dying. Empirical data potentially comparing open, legal access to physician-assisted death to secret, illegal practice in many localities—including the United States outside of Oregon, Australia, Belgium, Denmark, Italy, the Netherlands, Sweden,

and Switzerland—are now becoming available.[13] Of course, empirical data will not resolve the associated ethical or religious questions, but they will help to resolve some of the more secular issues around relative harm and benefit from legalization of assisted dying.

One of the positive outcomes of the debate about legalization of physician-assisted suicide is that other last-resort options have been considered—and, in some cases, legitimated.[14] There is growing acknowledgment that some patients experience unacceptable levels of suffering toward the end of their terminal illness, even though they are receiving state-of-the-art palliative care, and that some of these patients are capable of making rational decisions to hasten death (that is, they are not all clinically depressed or delirious).[15] For example, patients are allowed to discontinue life support as part of their right to bodily integrity, even when their desire is to die sooner rather than later. Patients who may have been taking a lesser amount of opioids for their pain so as to maintain alertness at one point in their illness may at a later stage request or accept more risk of sedation to achieve better pain relief as death approaches.

Two new options of last resort, voluntarily stopping eating and drinking and terminal sedation, have now been recognized as legally acceptable and are beginning to be more completely discussed from ethical and religious perspectives.[16] Voluntary cessation of eating and drinking involves a conscious choice to hasten death by a severely ill person who is still capable of eating and drinking. It is viewed ethically by many as a variant of the right to refuse treatment, as part of an individual's right to bodily integrity. Terminal sedation, which involves sedating the patient to unconsciousness (to allow an escape from suffering) and then withholding or withdrawing hydration and nutrition, is generally reserved for imminently dying patients whose physical suffering is severe and otherwise unrelievable. Sedation to the point of unconsciousness is viewed by many as aggressive symptom palliation with the intent to relieve suffering (therefore consistent with the doctrine of double effect), and the withdrawal of life-sustaining nutrition and hydration as part of the right to bodily integrity. Of course, either or both of these acts could be used intentionally to hasten a wished-for death and therefore be consistent with physician-assisted suicide or even voluntary active euthanasia, which makes these practices problematic for some clinicians and patients even if they are legally permissible.

Becoming more explicit about the acceptability of these last-resort practices has been an important contribution to enhancing end-of-life options for many patients. It acknowledges that tough cases of unacceptable suffering exist, and it reinforces clinicians' obligation to respond to suffering.[17] Additional options

can be offered to patients who otherwise would have no acceptable possibilities. For patients who are morally opposed to physician-assisted suicide yet nonetheless find themselves in intolerable clinical circumstances, these alternative last-resort practices may provide acceptable options to allow them to live (and die) on their own terms.

The possibility of a predictable escape from suffering if it becomes overwhelming is important to many patients,[18] especially those who have witnessed bad deaths in loved ones toward whom the medical profession was unable or unwilling to be responsive. This fear is probably the driving force behind the desire for legalization of physician-assisted suicide. Patients will speak about this when asked questions like, "As you look to your future, what are your biggest fears?" or "What kinds of deaths (good or bad) have you seen among your family or friends?"[19] Having this conversation relatively early on in a patient's potentially terminal illness lets the patient know that the clinician is not afraid of the dying process and provides opportunity to educate the patient about all the advances palliative care has made in terms of addressing pain and other symptoms. Some patients, however, may push the family or their medical providers further by asking questions like, "If my pain becomes intolerable, will you help me die?" Sometimes this will be a general exploration of the extent of commitment not to abandon,[20] but at other times it may include explicit exploration of what last-resort options can be supported. We know from the Netherlands that only about one in nine patients who explore the option of physician-assisted dying actually dies in this way. Patients who know that their doctor is a committed medical partner, and that acceptable medical options are available to address their fears and concerns, will then have the freedom to spend their time and energy on other more vital matters as they are dying. Those without this knowledge and commitment are left to wonder fearfully how their final weeks and months might unfold.

Usually, even when a physician has promised to be responsive in helping a patient die, careful delivery of palliative care and then hospice is sufficient to facilitate an acceptable, if not always ideal, death. Anecdotal evidence suggests that many patients try to protect their physicians and family members from legal risk even at the cost of their own suffering. Yet there will be cases in which suffering becomes severe and unacceptable, and a patient becomes ready to die sooner rather than later and is willing to ask for help. All such patients should be assessed in a similar way to ensure that all reasonable palliative care options have been considered, no matter which last-resort options are also being contemplated.[21] Have pain or other physical symptoms been adequately addressed?

Has the patient become depressed in a way that is distorting his judgment? Has a family or spiritual crisis developed?[22] If a careful assessment finds none of those elements present, is the request genuine and in proportion to the degree of the patient's suffering? Here the safeguards and second opinions of an open process become invaluable.[23] Whether the physician is considering stopping life support (legal) or providing medication that can be taken as an overdose (in the United States, illegal outside of Oregon), he or she must recognize that the patient is likely to die as a result of this decision, so it should be approached with the utmost care and caution. As always, safeguards for any of these last-resort practices must balance invasiveness and safety.

Once the assessment has been carried out to ensure that all reasonable palliative care alternatives that the patient is willing to accept have been considered and that the patient is clear about the request and the implications for him- or herself and the family, then a decision must be made about methods. The method chosen should be the least invasive and risky for the particular patient, taking into account his or her values and clinical circumstances. If the method includes physician participation, the physician's values must be taken into account, as well. If a physician is unwilling to participate in a legally accepted option for which the patient otherwise would qualify and which he or she desires, then the physician is obligated to offer to transfer the patient's care to a qualified physician with different views and values. The physician must not entrap patients by seeming to promise a physician-assisted death but then reneging on this promise.[24] If a physician is aware of all the last-resort options and is opposed to granting a request for assisted suicide by a particular patient, the physician might explore those options that he or she *can* support to see whether common ground can be found. Clearly, physicians should attempt to extend themselves to remain responsive to such suffering patients and their families, but that should not include violating fundamental personal moral values for either the physician or the patient. On the other hand, it is imperative that we now recognize that the patient's fundamental moral values may include physician-assisted suicide and that this option, for those who are dying, should be part of recognized law.

Although issues around legal access to physician-assisted death remain complex and controversial, we support the following conclusions based on the information presented in the preceding chapters:

- Excellent palliative care must be the standard of care for those who are severely ill and dying. It can address, and sufficiently relieve, most but not all suffering that accompanies the dying process.

- Strong philosophical, ethical, and religious principles—especially autonomy, mercy, and nonabandonment—support access to physician-assisted death as a last resort for those circumstances in which suffering becomes intolerable to a dying patient who has access to palliative care.
- When conflicts about values exist in end-of-life care, it is the patient's values that count most (it is his or her death, after all), followed by those of the family (who have to make sense of the decisions that have been made) and then those of the health care providers (if it involves their participation). In areas in which there is no societal consensus about permissible versus impermissible actions, patients, families, and their health care providers should be given as much leeway and support as possible as they face these difficult decisions.
- Traditional distinctions between killing and letting die, or between actively and passively assisting death remain controversial, and are not conceptually helpful by themselves in distinguishing between acceptable and unacceptable methods of assisting death.
- Patients' motivations for seeking physician-assisted death come from multiple sources, including illness-related symptoms and loss of function, desire for control and loss of sense of self, and fears about future losses. The first step in evaluating any request should be to fully explore its underlying meaning and the reason it is emerging at a particular point in time, in the context of this individual patient's personal values and culture.
- Patients requesting a physician-assisted death should be carefully evaluated for depression and other medical disorders that could be interfering with their decision-making capacity, but it should not be assumed that they lack capacity simply because they are asking questions about a practice that many disagree with or find uncomfortable to talk about. The clinical challenge is to learn to talk openly with such patients about their suffering and how they see their future and to respond as constructively and compassionately as possible.
- Although relatively few patients actually receive physician-assisted suicide, knowing about it as a possibility (as well as knowing about other last-resort options, such as stopping life-sustaining therapy, terminal sedation, or stopping eating and drinking) is important to many who fear hard death and need to know that they could have some choice in the process.
- Physician-assisted suicide should be viewed in the context of other last-resort options in which death is hastened, including discontinuing life-sustaining therapy, terminal sedation, and cessation of eating and drinking. The challenge clinically is to respond appropriately to the particular patient's clinical circumstances in light of his or her values and those of the family and the physician.

• As presented in detail in part 3 of this volume, six years of data from Oregon and three comprehensive studies spanning sixteen years from the Netherlands provide strong empirical evidence that a legally tolerated practice of physician-assisted death can be controlled. In both settings, physician-assisted death comprises only a small percentage of all deaths, which has been stable over time (Oregon less than 1 percent and the Netherlands about 3 percent); and, as the articles from the Netherlands have clearly shown, there has been no pattern of widespread abuse. In Oregon, as noted earlier, 85 percent of patients who died under the Oregon Death with Dignity Act were simultaneously enrolled in hospice programs, showing the potential compatibility of the two approaches. Furthermore, improvements in end-of-life care since implementation of the Death with Dignity Act have included the highest rate of at-home deaths in the nation; high use of prescribed opioids; high referral rates to hospice programs; comprehensive, statewide do-not-resuscitate policies; and a high level of public awareness of end-of-life options.

For those who do not reject the practice of physician-assisted death as a last resort on moral grounds, the main empirical question is whether an open, legally regulated practice is safer and better for patients than the more secretive, arbitrary practice that is currently present in the rest of the country. The experience from Oregon attests to the potential compatibility of improvements in palliative care and limited legal access to physician-assisted death. Whether Oregon's experience will be replicated in the rest of the country depends on how and when similar legislation is passed in other states. For those of us who believe these practices are not only compatible but complementary, the data from Oregon are reassuring and motivating.

In our opinion, physician-assisted death should represent a small but critical piece of a larger puzzle of improving end-of-life care for all dying persons. In the absence of universal medical insurance coverage, the first step in working with patients who are nearing death, whether or not they are exploring the possibility of an assisted death, is to ensure they have access to the best medical care possible. We must all join together in working toward improvements in palliative care and hospice, in hopes of making them accessible to all seriously ill patients.

Should we wait to consider the option of legal access to a physician-assisted death until we have solved the problem of universal access? In the interest of fairness to those patients who are suffering intolerably in the face of excellent palliative care and are requesting this kind of assistance now, the answer should be a resounding no. We do not withhold expensive, marginally effective treat-

ments for the few who might possibly benefit from them because so many lack coverage. Similarly, we do not prevent patients from stopping potentially effective treatment because they may be intentionally seeking to hasten their death or because others might not have access to effective treatment. Working with patients who are considering stopping life supports can and should be challenging, as they will most likely die as a result of that decision. But that does not mean that we should not listen carefully to their requests and do our best to respond. The same is true for patients who seek aid from their physicians in dying. The best protection we can offer is not absolute prohibition but rather to require full disclosure, second opinions to ensure the adequacy of palliative care and the careful assessment of patient decision-making capacity, involvement of experienced clinicians, and open documentation for study and review.

Vulnerable patients are asking us to listen to their requests with an open mind and heart and to keep their values and priorities at the center of the decision-making process. After all, this is a process driven by the experiences of dying patients and their families. Patients who begin to experience a bad death need access to experienced palliative care consultants who can make sure everything possible is being done to address their suffering, and make it tolerable. They need committed medical partners who will help them explore all potential alternatives but also address the reality that sometimes death is not the enemy. People who are terminally ill do not have a choice about whether to die, but they are asking for some choice and control over *how* they die. For many, potential access to a physician-assisted death allows reassurance that there could be an escape that they may never need. For a few who reach a point at which continued living becomes unacceptable and personhood is rapidly disintegrating, open access to a physician-assisted death can be vital to maintaining dignity and meaning at death.

## Notes

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